Caring for Diverse Populations: What you need to know about LGBTQ Patients

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Hello
my name is
Mandi
my pronouns are
She, Her
Disclosure

I have no disclosures.
Acknowledgments

• National LGBT Cancer Network
• LGBT HealthLink
• My staff
• My kids (and fur babies)
Learning objectives

• Describe unique risks & challenges for LGBTQ patients
• Improve communication with diverse patients
• Create a welcoming environment for LGBTQ patients
• Describe palliative care considerations for LGBTQ patients and caregivers
Terms

pansexual
queer
LGBTQIAA+
gender variant
two spirit
genderqueer
DSD/Intersex
SGL
Ensuring Compliance with Requirements Revised Medicare CoPs
As of January 18, 2011, in order to comply with the revised CoPs, hospitals participating in the Medicare Program must:

» Adopt written policies and procedures concerning patients’ visitation rights, including any clinically reasonable and necessary restrictions or limitations on visitation;

» Provide notice to patients or their support persons (where appropriate) of their visitation rights, including the right to receive visitors designated by the patient. A patient may designate virtually anyone – a spouse, domestic partner (including a same-sex domestic partner), another family member, or a friend. The notice must also advise of any time;

» Not restrict, limit, or deny visitation privileges based on race, color, national origin, religion, sex, entity, sexual orientation, or disability;

» Ensure that all visitors enjoy full and equal visitation privileges consistent with the patient’s preferences;

» Respect the rights of a same-sex partner as a patient representative to make decisions on behalf of his or her partner with respect to visitation if the patient is incapacitated. Documentation to establish representative rights in order to exercise the patient’s visitation rights should be required only in the limited circumstances when two or more individuals claim to be an incapacitated individuals’ support person;

American Health Lawyers Association and Human Rights Campaign, 2012
Advancing Effective Communication, Cultural Competence, and Patient- and Family-Centered Care for the Lesbian, Gay, Bisexual, and Transgender (LGBT) Community

A Field Guide

The hospital prohibits discrimination based on age, race, ethnicity, religion, culture, language, physical or mental disability, socioeconomic status, sex, sexual orientation, and gender identity or expression.
How many are we?

• There are an estimated 9 million lesbian, gay and bisexual individuals in the United States

• More than the population of New Jersey

Gates, 2011
93% of all U.S. counties

Gates and Cooke, 2010
Truth

Sexual and gender minorities experience:

• the highest tobacco and alcohol use of any population, increasing risks for cancer
• poorer mental health including anxiety, depression and suicidal ideation
• avoidance and denial of medical care
• family rejection and social stigma, which contribute to high levels of distress and low social support
Cancer experience for sexual and gender minorities

Diagnosed at later stage

Closeted during cancer treatment

Magnified stress

Social support & spectrum of support
Health care experiences
Heteronormative, cisnormative care
Discrimination in health care

Among physicians who identify as LGBT…

1 in 2 reported hearing derogatory comments about LGBT individuals

1 in 3 reported witnessing discriminatory care of an LGBT patient

Eliason, Dibble, & Robertson, 2011.
Discrimination among trans people

- 1 in 4 Trans people postponed care or did not seek preventive services due to discrimination.
- 1 in 5 Trans people were refused medical care due to their transgender status.
- Trans people of color denied care more often.

James et al., 2016.
Lack of provider knowledge

Insufficient training to address the health care needs of LGBTQI individuals

Lack of knowledge about unique health needs of LGBTQI individuals

Rounds, McGrath, & Walsh, 2013; James et al., 2016.
Survivor’s perspectives

Making a treatment decision while also living with AIDS

Need for tailored information/support

Pratt-Chapman, 2017
The Role of Bias
Medical school student bias

• Over 80% of first year medical students expressed implicit bias against lesbian/gay people
• Nearly 50% expressed explicit bias

Burke et al., 2015
Denying care

“I really expected him to have a little more professionalism. When his face turned red and he couldn’t look me in my eye he had totally lost control. He left the room and didn’t come back in. He sent a nurse in after that. [I thought] Am I the first lesbian to walk through this door?”

Matthews, 1998
Denying care

“...My doctors will discuss information with my partner, but they are less willing to provide her with support. For example, after my latest surgery the doctor didn’t even speak to her. She was just left there waiting. She’s a nurse herself and was shocked, very shocked.”

Matthews, 1998
Self-reflection: Privilege
Learned behaviors

FOR THE LOVE OF ALL THAT IS GOOD AND HOLY IN THIS WORLD...

We had dinner. It was good.

STOP DOING THIS!
Perception of truth

Although it may seem impossible to believe, the squares marked 'A' and 'B' are actually exactly the same shade of grey.

Edward H. Adelson
Sexual and Gender Minorities: Invisible in research

- General lack of clinical and research data on health needs of LGBTQI people
- Ignores realities of diverse experiences of LGBTQI individuals
- Poor understanding and communication of the health risks and disparities experienced by LGBTQI communities
Palliative care experiences
Bereavement

• Loss of primary relationship
  – Less likely to seek appropriate healthcare
  – Worse health
  – Less likely to be employed
  – Greater mortality

Bristowe, Marshall & Harding, 2016
Unique considerations

• Greater isolation, particularly among the elderly
• Fear of discrimination
  – 34% of lesbians & bisexual women (n=522) in a UK study were concerned about EOL arrangements
  – 24% expected barriers related to sexual identity

Stonewall, 2014
Fear

Even though I was not treated badly, I always had that fear that I could be treated badly … there is always a threat that you carry around in your heart that they can be bad to you, “

Hash, 2006
Lack of acknowledgement

“I was mentioned in the death notice, you know, as his … after his mother, as his faithful friend.”

Glacken & Higgins, 2008
Exclusion

I wasn’t seen as having any particular role. I was just a friend who was visiting him [in hospital] … they sent for his sister and when she arrived we got more and more information.

Glacken & Higgins, 2008
Isolation

I knew he wanted burial and he wanted to be buried next to his mother. He ended up being cremated (which) was totally against his religion … I couldn’t stop them but it was like strangers organizing his funeral; I was his family … But he never wanted it to be known that he was gay. And I respected that, so he wasn’t out, I wasn’t out then either. I couldn’t talk to my family … they thought David was just a friend. I was a right mess. I had no-one to turn to.

Almack, Seymour, & Bellamy, 2010
Shadow of HIV and AIDS

If anyone asked me questions or approached me directly, I’d give them an honest answer about my sexuality or about us being together. But when it came down to the disease of AIDS, that stigma was a terrible black cloud. You aren’t allowed to tell anybody about it for fear of losing your job or fear of being closed out of a group of friends. And when you need the support the most, people are running from you.

O’Brien, Forrest, & Austin, 2002
Inability to say goodbye

“Of course, they wouldn’t let me in the room, but I found a little corner desk where I could at least see her feet, which wasn’t much … so I never got to say goodbye.”

Bent & Magilvy, 2006
“What can I do about it?”
Check your assumptions

- What are your immediate reactions?
- How might those reactions influence the patient’s experience of care?
- Do not assume heterosexuality
- Do not assume cisgender status
- Do not assume who is and who is not the patient’s caregivers
- Ask clinically-relevant questions
- Do not ask questions out of curiosity
How LGBTQ patients disclosed

“If you were out to your health team, how did that happen?”

The **form** gave me the opportunity to specify my sexual orientation/gender identity 19%

The provider **asked** me a direct question about my sexual orientation/gender identity/the nature of my relationship with the person with me 17%

I brought up the subject **myself**, including as a way to correct a mistaken (heterosexual) assumption made by the provider or healthcare worker 58%

**Someone else** told the health care provider about my sexual orientation/gender identity 3%

*Margolies & Scout, 2013*
Acknowledge your patients

• Acknowledge history & reality now
• Ask about sexual orientation, gender identity, partner-status, sexual behavior
• Reflect the patient’s words
  – Name
  – Pronouns
  – Body parts
• Be genuine
How do I ask sexual orientation questions?

• Do you think of yourself as?
  – Straight
  – Lesbian, Gay or Homosexual
  – Bisexual
  – Something Else
  – Don’t Know

• What is your Current Relationship Status?
  – Married
  – Partnered
  – Single
  – Widowed
  – Divorced
  – Other
How do I ask gender identity questions?

• What is your current gender identity?
  – Male/man
  – Female/woman
  – Trans Male/ Female-to-male
  – Trans Woman/ Male-to-female
  – Genderqueer
  – Other

• What sex were you assigned on your original birth certificate?
  – Male
  – Female
  – Intersex
Be open and nonjudgmental

• Be patient to allow for response
• Display open body language
• Follow patient lead in terms of eye contact
• Look up from your screen
• Be respectful, professional & supportive
Ask permission to store information
Be an advocate

- Broker patient-provider communication
- Educate other team members and staff about needs of LGBTQ patients
- Tailor conversations/materials
- Identify system changes that need to happen to create a welcoming environment
Show you have a safe environment

- Nondiscrimination policies
- Rainbows
- Brochures
- Posters
- HRC Healthcare Equality Index
- Staff training
- Resources
Create inclusive spaces

Gender neutral bathrooms are not just kind, they **OFFER SAFETY** to transgender and gender nonconforming people.
Avoid micro-aggressions

- Gossiping
- Refusing to care for a patient
- Sending a patient a chaplain because you are concerned with their spiritual well-being
- Name-calling, even between peers
- Rudeness, condescension, insensitivity
- Trivializing concerns about differential treatment
- Having no place to indicate same sex partner or SOGI
- Claiming SOGI is irrelevant
It’s ok to make mistakes

Stepping on toes is the unintentional pain caused by a **NEWFOUND WILLINGNESS** to be close with people who are different from you.
Taking a closer look
References

- Bristowe, K., Marshall, S., & Harding, R. (2016). The bereavement experiences of lesbian, gay, bisexual and/or trans* people who have lost a partner: A systematic review, thematic synthesis and modelling of the literature. Palliative Medicine, 30(8), 730-44.
References

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